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ABSTRACT

This report discusses the outcomes of a study that investigated the effects of a gluten-free diet on three males with autism between the ages of 5 to 8 years old. All subjects were also participants in prior studies on the effects of the gluten-free diet on the learning processes of children with autism in an applied behavioral analysis program. The three subjects on the gluten-free diet had an average of 2.1 years experience of applied behavioral analysis. Rates of learning of five behavioral targets of the participants involved the number of attempts required to reach a behavioral target during a pretreatment baseline and at 9 months after the initiation of the gluten-free diet. The total number of attempts for the last five targets mastered following 6 months and 9 months on the gluten-free diet comprised the post-treatment scores for each participant. Both the between subjects and within subjects measures revealed no significant increase in the rate of learning following the implementation of the gluten-free diet over a 9-month period. The report discusses the etiology of autism, the background of the gluten-free diet movement, behavioral analysis, the search for new treatment strategies, and treatment effects of facilitated communication. (Contains 30 references.) (CR)

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Changes in Rate of Learning in Autistic Children following 9 Months on a Gluten-Free Diet

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Abstract

Abnormal metabolism of the proteins found in gluten is postulated to produce autistic symptoms. Due to this suspected link between allergy to gluten and autistic behavior, many families have eliminated gluten from their children's diets. Since implementing gluten-restrictive diets, many parents report observing drastic behavioral improvements in their children, including reduced aggression and increased compliance.

This investigation was an extension of an ongoing examination exploring the effects of the gluten-free diet on learning in autistic children in an applied behavioral analysis program. Although significant interim effects were observed in previous studies, the analysis of data at 9 months failed to support the diet's efficacy.

The failure to observe a significant performance change over the 9 month diet period, using either the within or between-subjects analysis, raises questions about the reliability of this treatment's effectiveness. Given the history of oversold, unsubstantiated treatments for autism (e.g., facilitated communication), further research is recommended to clarify the long-term impact of the gluten-free diet on the performance of autistic children.

Introduction

Autism is a neurological disorder marked by severe impairment in social, emotional, and intellectual functioning. Autistic syndromes are variously referred to as childhood autism, infantile autism, autistic disorder, pervasive developmental disorder, and childhood psychosis. The basic criteria include abnormal social relatedness, abnormality of communication

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development, repetitive patterns of behavior, and abnormal stimuli responses (Edelson, 1997). Autistic individuals also have difficulty in seeking comfort, imitating others, and participating in imaginative activities.

Etiology

The cause of autism is still unknown; however, there are varied theories as to what induces this behavioral syndrome. One theory postulates a genetic factor in autism, and there is supportive research evidence showing higher concordance among monozygotic twins than dizygotic twins. If the main causes are environmental, then the concordance rate should be the same for both types of twins. Biological children of autistic individuals are at increased risk for the disorder. Researchers in Utah examined 11 families in which the father had autism, and out of the 44 offspring, 25 of the children had autism or autistic tendencies (Edelson, 1997). Autism occurs in siblings of autistic children 2.7% of the time, and autistic traits will often show up mildly in the parents, siblings, and other relatives of the autistic child (Wolf-Schein, 1997; Noreen et al., 1990; Landa et al., 1992).

Children with autism also have structural abnormalities in their brains. The limbic system is immature, which causes problems with emotions, aggression, and learning. The transmission of nerve impulses through the brain is also abnormally slow (McClelland et al., 1993). Courchesne (1995) found two areas of the cerebellar vermis to be extremely small in 86% of autistic subjects and abnormally large in 12% of autistic subjects. Due to these abnormalities, the children may have deficient ability to focus their attention to follow the verbal cues that signal changes in social communication (Wolf-Schein, 1997).

Autistic individuals also differ from others in terms of neurotransmitter activity. Research suggests that they have unusually high levels of serotonin and beta-endorphins (Panksepp, 1979). The fact that autistic children appear to have a higher pain threshold could be due to these elevated levels of beta-endorphins, which are opiate-like substances in the body that allow tolerance of pain .

There is also evidence consistent with a possible viral etiology. If a female is exposed to rubella during her first trimester of pregnancy, then she has an increased risk of having of child with autism (Edelson, 1997).

Concerns about environmental precursors to autism include the possible effects of toxins and pollution on the developing child. In Leomenster, Massachusetts, there is a high prevalence of autism surrounding a particular manufacturing factory. The highest percentage of cases were found in the homes down wind from the plant smokestacks (Edelson, 1997).

Cognitive conceptualizations of autism see the disorder as a defect impairing the highest level of cognitive processing

(Frith, 1993; Wolf-Schein, 1996). This defect results in autistic children not being able to think about mental states, such as beliefs and the perspective of others (Baron-Cohen, Iesile & Frith, 1986). When autistic children were handed pictures of people to sequence, they did poorly because in order to complete the sequence correctly they had to comprehend the beliefs of others.

A more recent theory regarding the cause of autism concentrates on a link between allergies and behaviors. Autistic children have metabolic difficulties with gluten or wheat products, and casein or milk products. Research theorists have proposed that abnormal functioning of opioid peptides promote the emergence of autistic symptoms. Analysis of 24 hour urine samples from children with autism have shown increased levels of peptides (Reichelt et al., 1986). These peptides, which are short chains of amino acids, derive from the incomplete digestion of gluten, which breaks down into gluteomorphins, and of casein, which breaks down into casomorphine. For most people, the digestion of proteins occurs through the intestines, however, for the autistic child this digestion is incomplete and results in the characteristic traits of the disorder. Most of the peptides are released through the urine, but a small amount still manage to escape into the blood stream and cross into the brain, which is hypothesized to alter normal brain transmission (Lewis, 1994).

Gluten-Free Diet

After researchers discovered the possible contribution that gluten made to autistic symptoms, many families removed gluten from their children's diet. Glutens are proteins found in plants which are members of the grass family, including wheat, oats, barley, rye, tritical, and their derivatives (Lewis, 1994).

The beginning of the 1980's provided the first evidence that similarities exist between the behavior of animals on opioids and the symptoms of autism. Panksepp (1979) suggested that autistic individuals may have elevated levels of opioids, such as beta-endorphins. In 1986, Reichelt analyzed the urine samples of 24 autistic children, and found increased levels of peptides. Following this observation, in 1988, Gillberg produced evidence of elevated levels of opioids in the cerebro-spinal fluid of autistic individuals (Lewis, 1994).

Autistic children were analyzed in 1990 by Reichelt and treated with either gluten-free and casein reduced or casein-free and gluten reduced diets. Of the 15 participants, 5 had increased levels of antibodies to casein or gluten. The diet allowed for the decrease in urinary peptide secretion, and the improvement in several behavioral areas, including a decrease in seizures (Reichelt, 1990).

Knivsberg et al. (1995) have provided initial results on a study of a gluten-free diet as a treatment for autism. The diet was applied to 15 subjects with autistic syndromes. All the children participating had an increased level of peptides in

their 24 hour urine samples and had pathological urine patterns. The child participants were given behavioral, psycholinguistic, and cognitive tests before they started the diet and one year later.

After the first year of the diet, the children were communicating and responding more actively. They experienced a greater ease with emotional expression and with the formation of social relationships with other children. Appropriate play increased, while odd movements, fear, and avoidance of physical contact decreased. Also the urine samples were tested after one year and revealed normal urine patterns and peptide levels. Language was assessed via administration of the Illinois Test of Psycholinguistic Abilities (ITPA). All subscales, except for short term memory, increased after the first year of the diet. A measurement of cognitive ability showed that the children used their cognitive abilities in a different way when they were on the diet. Parents and teachers observed a change in the children's motor abilities, due to a new awareness of their bodies. Bladder control increased, and their high pain threshold decreased.

Knivsberg et al.(1997) also performed a study on the effect of the dietary intervention after four years. The researchers looked at the original group of child participants placed on the gluten and casein free diet. The children who remained on the diet after the initial year continued to develop, while those who discontinued the dietary intervention regressed. The Illinois Test of Psycholinguistic Ability scores increased beyond the expected level. When comparing the scores from the first year with those from the four year follow-up, similar profiles were displayed by the children however at higher functional levels. After four years there was improved social interaction, less social isolation, more communicative ability, and a decrease in peptide levels (Knivsberg et al., 1997)

The urinary samples of children diagnosed with autism syndromes, from several different countries, were also analyzed by Knivsberg (1997). The peptide excretion was examined by a new HPLC method, and showed that the amount was statistically the same among all nationalities. When the gluten and casein were removed from the diet of these children, they showed demonstrable improvements on different tests (Knivsberg et al., 1997).

Many families who have experienced their child going through the diet initially report that the child's behavior regresses during the beginning stages of the gluten-free diet. Some negative effects reported include upset stomach, bad temper, and clinginess. A period of one year is suggested to see if the diet is working, however, most likely after three months if a gluten-free diet has not produced results, it will not. For the children who improve due to this diet, the restriction of gluten is highly worth the sacrifice. For most, aggressive tendencies cease and communication and socialization expands. It is generally assumed that these functional changes were due to direct or indirect modifications in the pharmacological effects of the peptides,

produced by reduced exposure to gluten (Knivsberg et al., 1995). The link between allergies and behaviors has begun to receive a great deal of attention, not just as an intervention tool but also as a possible preventive measure. The diet however should not be a substitute for a previous treatment method, but rather a supplement and additional tool (Knivsberg et al, 1995).

Behavioral Analysis

The literature on autism contains numerous etiological hypotheses and there is no certainty as to which model best accounts for this severe impairment. Therefore, several competing intervention strategies have emerged over the years. A majority of these interventions have met limited long term success (DeMeyer, Hingten, & Jackson, 1981; McEachin, Smith & Lovaas, 1993). Research, however, has shown that functioning has improved for autistic children following intensive behavioral intervention (Lovaas, 1987; McEachin et al, 1993). The applied behavioral analysis program, developed by O. Ivar Lovaas, has produced favorable and long-lasting results, and has been reported as having the best outcomes among all current methods (CSAAC, 1997).

The outcomes of O. Ivar Lovaas indicate 47% of the children who participate in this intensive intervention program will achieve normal IQ and educational placement evaluations. The children who are unable to achieve the normal intellectual levels still improve in general intellectual areas. Even the smallest improvement for these children allows learning to take place in less restrictive environments and classrooms (CSAAC, 1997).

Dr. Theodore Shapiro and Dr. Margaret Hertzig (1995) of the New York Hospital-Cornell Medical Center, claim that the outcomes of this method are astonishing. After two siblings took part in the applied behavioral analysis program of Dr. O. Ivar Lovaas, they no longer fit the diagnostic criteria for autism and they no longer displayed the social, personal, and language difficulties that accompany this disorder.

A study examining the long term outcome for autistic children who had received early intervention behavioral treatment revealed evidence of continued achievement over time, and significant enduring intellectual gains (McEachin, Smith, & Lovaas, 1993). These researchers took a group of 19 autistic children, under the age of four years old, and provided them with forty hours of behavioral treatment for two years. When the children reached the age of seven, they were re-evaluated. The children had gained an average of 20 IQ points, and nine out of the nineteen had completed first grade. The control group for the study consisted of forty untreated autistic children. When re-evaluated, only one out of the forty control group participants had reached a normal level of intellectual functioning. The results of the study showed that those who had received the early intervention continued to surpass members of the control group (McEachin, Smith,& Lovaas, 1993).

This behavioral approach is now considered to be the most popular and effective educational treatment for autism. This treatment provides concrete criteria for measuring skill mastery. Behavior of children participating in this treatment is evaluated systematically, permitting detection of subtle changes in the rate of achievement over time.

The discrete trial is the basic three-part teaching unit used in the applied behavioral analysis program to maximize learning in developmentally disabled children. The discrete trial consists of the discriminative stimulus, the response, and the reinforcing stimulus. Through the use of these trials, along with reinforcement, prompting, and shaping, this program allows the modification of unwanted behaviors. The approach itself includes procedures that emphasize behavior enhancement and behavior reduction (Campbell, Schopler, Cueva, & Hallin, 1996). A central belief of this method is that reinforcement that enhances or reduces the behaviors should be contingent upon the behavior targeted. Therefore, the child should not be able to obtain the reward through other means or at other times besides therapy.

In order for a specific treatment plan to be created for the child, a detailed analysis of the relationship between the child and the environment takes place. From this point, the drills are chosen in order to strengthen or eliminate particular behaviors.

This behavioral treatment is extremely time consuming, and involves both the participation of family members and competent therapists. Overall, this early intervention program is aimed at enhancing the intellectual and social skills of these children so that they will be able to take care of themselves as they grow older, and have adequate socialization opportunities along the way (Niemann, 1994).

The Search for New Treatment Strategies

Even though the advantages of the behavioral treatment are numerous, the families of these children still search for additional means of dealing with this neurological disorder. They are constantly engaged in a desperate search for any new method that claims to work. The parents will turn to various types of traditional and non-traditional treatments in the hope of increasing their youngster's appropriate behaviors.

Other intervention methods include language and communication therapy, and auditory integration training. The two treatments which have received the majority of empirical support are behavior modification and the use of the vitamin B6 with magnesium supplements. However, the more controversial means of intervention include the use Ritalin and facilitated communication. Ritalin is the most widely prescribed medication for autistic children, however, because there have been no double blind controlled studies, it is difficult to verify its effectiveness (Edelson, 1997). Facilitated communication is considered unorthodox, but has attracted many adherents. With

this method the non-verbal child is given a means of communication, however it is unknown who is actually doing the communicating, the child or the facilitator.

Facilitated Communication

The research literature on facilitated communication illustrates the vulnerability of the autistic population to oversold, unsubstantiated treatment methods. With the emergence of facilitated communication in the 1970's came the hope that a miracle tool with startling results had been discovered. Previously nonverbal autistic children, with the help of a facilitator, were now apparently typing words and sentences with clarity and intellect. Once it arrived in the United States in the early 90's, families seized upon it, even though well-controlled efficacy studies had not yet been performed.

Facilitated communication is based upon the belief that autistic individuals have literacy and intellectual abilities, but are unable to utilize them due to their disabilities (Biklen, 1990; Biklen & Schubert, 1991; Cardinal, Hanson, & Wakeham, 1996). By means of facilitated communication, these masked competencies are assumed to be demonstrated. This method requires that a facilitator physically supports the hand, wrist, or arm of the individual, so that they can select particular pictures, words, or letters on the keyboard or alphabet board. This facilitation is hypothesized to allow the individual to communicate effectively (Weiss, Wagner, & Bauman, 1996).

During the early stages of using facilitation, the individual is completely dependent on the facilitator for stability and reliability of selections. However, as time progresses, the objective is to reduce this support. Eventually, the individual should be able to control their hand movements and independently make selections on the keyboard (Lapos, 1996).

Much of the debate revolving around facilitated communication concerns whether autistic subjects are actually the source of the message conveyed. Controlled research using double and single blind procedures have shown that without the assistance of the facilitator, the disabled individual is unable to respond accurately. Therefore it can be assumed that the responses are actually controlled by facilitators and not in fact by the disabled individuals.

Wheeler, Jacobson, Paglieri, and Schwartz (1993) took 12 autistic individuals competent in facilitated communication and assessed if the facilitators were unknowingly determining what was typed. Three conditions existed. The first condition allowed for assisted typing with the facilitator unaware of the stimulus content and the second involved unassisted typing. The third involved assisted typing with paired pictures that were unknowingly presented either the same or different to the participant and facilitator.

Out of the 180 trials there were no clear correct responses. During the trials in which the facilitator and the participant

received different stimulus cards, there were 12 responses correct to the cards shown to the facilitator and 0 responses correct to the participants cards. Vazquez (1994) found similar results when she tested the validity of facilitated communication while controlling for cuing. She concluded that the correct answers were typed only when the facilitator knew the answer. When controlled quantitative studies are performed, rather than qualitative studies, the results seem to be consistently negative and indicate that this method is not valid (Jacobson, Mulik, & Schwartz, 1995).

Another issue facing facilitated supporters of communication involves the potential misuse of the process. Following facilitated communication, many families have been confronted with allegations of sexual abuse or molestation of the disabled child. The facilitators believe they have come across evidence of abuse, and report the families to the authorities. A majority of the time the cases are terminated before extended prosecution or trial. Investigations usually show that the facilitator was influencing the communication, and that there was no factual basis for the charges.

Despite the negative outcomes and misuse, a few studies have demonstrated that facilitated communication can for some individuals be a valid form of treatment. An autistic individual took part in three independent trials, with the help of an uninformed facilitator. After the reading of short stories, the validation procedure took place. In two of the trials, the autistic individual answered specific questions correctly and accurately with the help of an uninformed facilitator (Weiss et al., 1996).

Another study involved over 3000 severely disabled students, in an attempt to validate facilitated communication under controlled, blind conditions. The students were asked to spell words while the facilitator was absent. The students were allowed to practice the test but not the actual words. Six weeks later, 74% of the students could correctly spell one or more of the words shown to them while the facilitator was absent, and half were able to spell two to five words. These results proved to be remarkable; with out facilitation these disabled individuals were able to reach high performance levels only after nine sessions (Cardinal, Hanson, and Wakeham, 1996).

Overall, facilitated communication research indicates that the facilitator may unwittingly be selecting the letters to spell out the particular message. The authorship is often in the hands of the facilitator, and not the disabled individual. Without the facilitator present, few advances have been made.

The initial acceptance of this treatment method prior to suitable outcome evaluation is alarming. Families must learn that treatment failures and shams exist. Due to their susceptibility, it is clearly possible that families of autistic children can be exploited by those eager to oversell untested treatment methods.

Empirically Validating The Gluten-Free Diet

Unlike the controversial method of facilitated communication, many outcome evaluations have supported the effectiveness of the gluten-free diet. Research has indicated that the gluten-free diet is associated with increases in the autistic individual's psycholinguistic and cognitive skills. It seems reasonable to assume that this same diet would increase the behavioral achievement of the autistic individual. Applied behavioral analysis is viewed as one of the most effective approaches to this disorder. This treatment provides concrete criteria for measuring skill mastery. Behavior of children participating in this treatment is evaluated systematically, which allows for the detection of subtle changes in learning rates. This investigation will compare autistic children's rate of learning structured target behaviors before institution of the gluten-restrictive diet with their performance after being on the diet for 9 months.

9-Month Analysis

Methods

Three autistic children, with ages ranging from five to eight years old, served as subjects. All subjects were also participants in the prior studies on the effects of the gluten-free diet on the learning on autistic children in an applied behavioral analysis program. The three subjects on the gluten-free diet had an average age of 6.7 years and an average of 2.1 years experience in applied behavioral analysis.

Rates of learning of five behavioral targets of three male participants, involved the number of attempts required to reach a behavioral target during a pretreatment baseline, and at 9-months after the initiation of the gluten-free diet were compared using a between-subjects and within-subjects analyses. The total number of attempts for the last five targets mastered following 6-months and 9-months on the gluten-free diet comprised the post-treatment scores for each participant.

Results

This study used both between-subjects and a within-subjects analyses to assess whether a significant performance change over the 9-month gluten-free diet period existed. Both the between-subjects and within-subjects one tailed t-tests revealed no significant increase in the rate of learning following the implementation of the gluten-free diet, over a 9-month period. The mean number of trials to mastery of task during the baseline observation was 5.93, and the standard deviation was 5.12. The mean number of trials to mastery of task at 9 months after initiation of the gluten-free diet was 5.84, with a standard deviation of 2.95 ($t=.04$; nonsignificant).

Discussion

The failure to observe a significant performance change between the baseline and the 9-month diet period, using either the between or within-subjects analyses, raises questions about the reliability of this treatment's effectiveness. This inability to replicate the results of earlier studies (indicating that a gluten-free diet is associated with continual improvement on the rate of learning of autistic children participating in an applied behavioral analysis program over a period of 1-month, 3-months, and 6-months) suggests that the diet may have a variable impact over time.

It seems premature to conclude on the basis of the learning rate data that the dietary restriction of gluten is associated with improved performance over time. Development of more reliable means of assessing the impact of the gluten-free diet on the potential for learning might clarify the inconsistencies across studies. Further research is needed to determine the long-term impact of the gluten-free diet on the performance of autistic children, in order to assist parents in making optimal treatment choices for their children.

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